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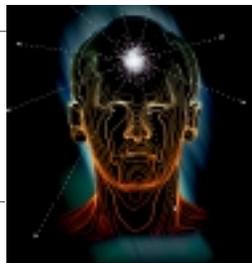
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FAX: 865/525-7917  
E-mail: editor@amputee-coalition.org  
Web site: www.amputee-coalition.org

President & CEO John Miller  
Executive Editor Nancy M. Carroll  
Associate Editor Rick Bowers  
Graphic Design Karen Jenkins

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# A MESSAGE FROM THE PRESIDENT



In 1999, the Amputee Coalition of America (ACA) published the first edition of *First Step-A Guide for Adapting to Limb Loss*, which was a rousing success. In fact, I received the following comment from a reader as the second edition was at press: "The first issue of *First Step*...is brilliant in its focus, scope and content...done...in a professional manner accompanied by breathtaking photography and flawless prose."

*First Step* provided a valuable service in using experiences of others to show amputees that they are not alone. In that sense, it was a logical extension of *inMotion*. It also provided useful listings of healthcare providers and resources for amputees.

With the second edition, our intent is to ensure that *First Step* is truly a resource - short on vignettes, long on useful "how-to" articles. The *First Step* Publications Committee - made up of ACA members, staff, board members, healthcare providers, and consumers - decided that this edition of *First Step* should follow a more chronological sequence in guiding the amputee through the myriad issues involved in making educated decisions about adapting to limb loss. Addressing these issues are some of the most knowledgeable authorities in the field.

While we realize that information, particularly information as relates to technology, soon becomes obsolete, we have included a futuristic look at technology. Additionally, although membership listings change daily, we have included an up-to-date (at press time) listing of ACA member prosthetists, facilities, support groups, and lifetime members.

We would surely be remiss in not acknowledging the funding that enabled the ACA to publish the second edition. If it were not for the grant to fund the National Limb Loss Information Center (NLLIC), *First Step* in its present form would not have happened. Thanks to the Centers for Disease Control and Prevention (CDC) for its visionary approach toward funding services for amputees.

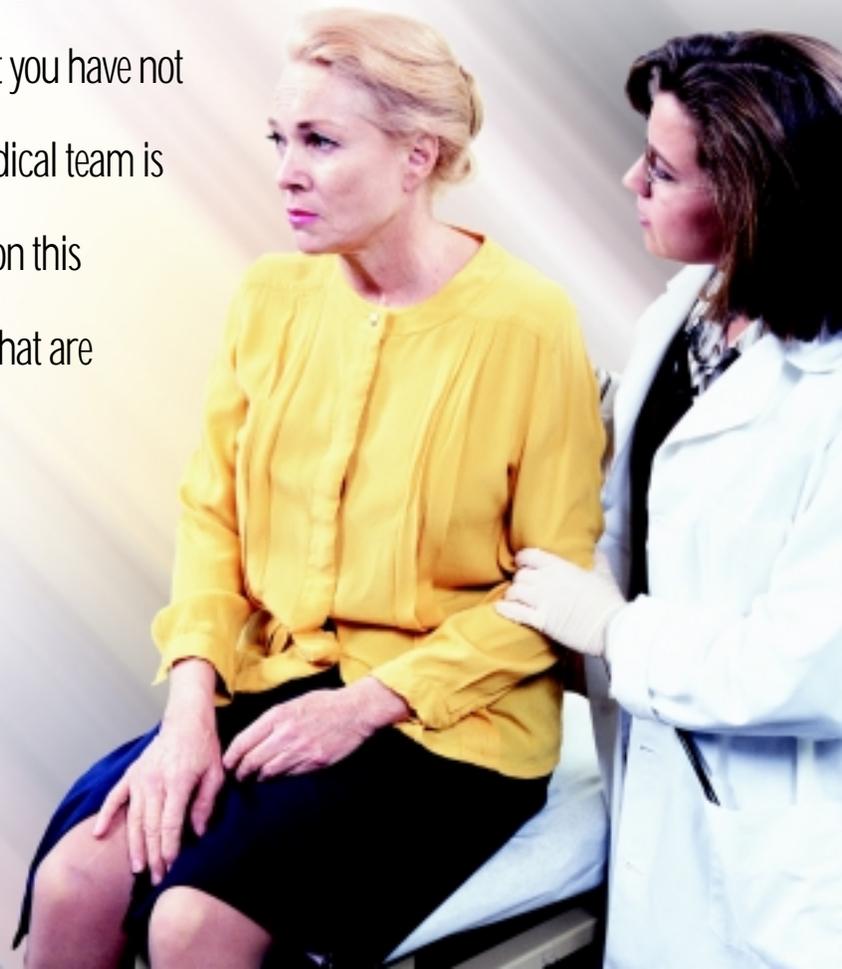
Finally, use *First Step* and tell others about it. Also, let us know what you think of it. We plan to publish *First Step* every other year, and it will continue to improve.

A handwritten signature in black ink that reads "Miller".

John Miller, MSSW  
President and CEO  
Amputee Coalition of America

# FACING AMPUTATION SURGERY

“We’re going to have to amputate your leg.” If you have just heard those words from your doctor, you probably have a whirlwind of emotions and questions running through your head. “Isn’t there anything else they can do? How long will I be in the hospital? What will I feel like when I wake up after the operation? Will I have to spend the rest of my life in a wheelchair?” Certainly, your family has many questions as well, and there are probably many questions that you have not even thought to ask yet. Although your medical team is certainly your main source of information on this subject, there are certain general concepts that are common to most amputations.



# LOWER EXTREMITY

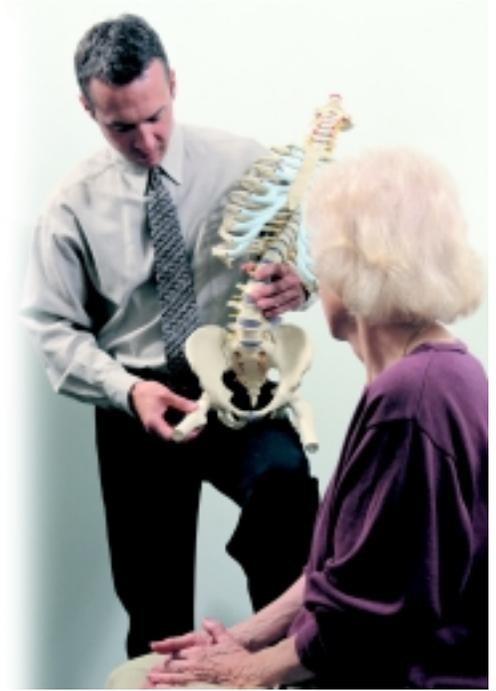
by Raymond Francis, CP

**I**s amputation really necessary? During the course of treatment to try to save your leg, your doctor probably told you that amputation was a possibility. Such a statement was not meant to scare you — it was made to prepare you for one of the various outcomes that might result. Now that the prospect of amputation is becoming a reality, you may feel as though you should be depressed that you are losing your leg. In reality, though, amputation is giving you a chance to remove something that is seriously threatening your health. Your doctor will try as hard as possible to save your leg, but when the treatments are not working, then it's time to save your life instead of your leg.

Think of it this way - your leg is no longer working for you the way it should, so it's time to say goodbye to an old friend that's no longer able to help you. In many cases, an amputation that is performed well, followed by a good prosthetic fitting, will result in less pain and more function for you. If you have ulcers that won't heal, or some other condition that is causing you pain with every step you take and is preventing you from living the life that you want to live, then having an amputation is taking a step toward improving the quality of your life — a very positive thing indeed.

## How much of my leg will be removed?

One thing that is important to understand is that there is no set place on a leg to conduct the amputation. Your condition is unique, and, therefore, your surgeon will need to determine the best place on your leg to amputate. Ideally, the part of the leg that remains (the "residual limb") should be as long as possible. A longer residual limb gives you a better lever with which to control your prosthesis; however, the surgeon also wants to make sure that there is enough blood flowing to the amputation site to ensure adequate healing. There's no point in leaving you with a nice long residual limb if it doesn't heal properly. You'll simply end up back in the hospital for more surgery. Therefore, the surgeon will have to make a compromise between achieving the longest possible residual limb, yet amputating high enough on the leg to make sure that the amputation site will heal properly.



Before your amputation, ask your doctor how he or she will determine where on the leg to amputate. One method is for the doctor to actually make a small incision at the desired amputation site as the surgery is about to begin, and then wait to see how well the blood flows. If the blood flow is insufficient for proper healing, then the doctor can make another small incision a little bit higher on the leg and check the blood flow again, repeating the procedure until adequate blood flow is located. You can be fitted with a prosthesis if you have a residual limb of almost any length, so the surgeon's goal should be to achieve the best combination of limb length and proper healing for you.

## What can I expect once I go into the hospital?

Once your doctor decides to amputate, you should be able to check into the hospital very soon unless there is some other condition like high blood pressure, diabetes, or a heart condition that must be addressed first.

Shortly before surgery, you will receive a sedative in your hospital room to help you rest and be calm. Then you will be transported on a gurney to the surgical suite, transferred to the operating table, and anesthetized. Once you enter a state of painlessness, the surgery will begin. As the procedure ends, the surgeon will insert a tube to allow fluids to drain out of your residual limb.





Once the operation is complete (after approximately one to four hours, depending on your condition), you will be transferred back on to the gurney and rolled into the recovery room. There the recovery team will administer pain medication and monitor your condition closely. After a couple of hours, you will be returned to your room.

When you wake up, you may feel as if your amputated leg is still there and that the amputation was not performed. I've even seen an instance where a visitor sat on the edge of a patient's bed (where the leg would have been), and the patient said, "Hey, get off my leg!" as if the leg were actually there. This phenomenon is known as "phantom sensation." Some patients are embarrassed to ask about this feeling – fearing that the doctor will think they're crazy. It is perfectly okay to ask your doctor about it, and rest assured phantom sensation will dissipate over time.

Within the first 24 hours after surgery, the drain tube will be removed from your limb. Also, you will probably be visited by a physical therapist during that first day. He or she will review a plan for your rehabilitation, and then will continue to visit you during your stay. The amount of therapy activity will increase with each visit according to how much you can tolerate.

The surgical dressing will be changed within the first 48 hours. The dressing may be changed daily during your stay, usually when the surgeon visits you to examine the site for signs of healing. Above-knee amputees typically heal a little more quickly than below-knee amputees, simply because an above-knee amputation occurs higher on the leg, where the blood vessels are larger. More blood flow equals better circulation, which leads to faster healing.

At some point during the first three to five days, you will be taken off intravenous drugs and started on oral pain medication. During this time, the

surgeon has probably been discussing your condition with a prosthetist, the person who will eventually fit you with your prosthesis when you have healed sufficiently. The prosthetist will typically apply a shrinker, a compressive device that could be anything from an elastic bandage to something more sophisticated. The purpose of the shrinker is to keep swelling down, to facilitate circulation, and to prepare your limb for prosthetic fitting. The shrinker is typically changed a couple of times a day.

Within seven to 10 days, the average patient is ready to head home. The length of stay could be longer if you have a heart problem or some other condition that could slow your recovery time. It is, of course, in the hospital's best interest to allow you to stay until you are adequately recovered. Otherwise, you might very well end up right back in the hospital.

### Will I be in a lot of pain?

You will probably experience less pain than you might expect. The scenes we've all seen in movies where the patient bites down on a bullet and swills a bottle of whiskey to dull the pain of an amputation are a thing of the past. There have been significant advancements made in pain management during the past several years, resulting in very effective (yet less addictive) pain medication.

### How will I be able to get around after my amputation?

After the surgery your medical team will try to get you up and about as soon as possible (with their assistance, of course). They aren't trying to be cruel by "kicking you out of bed." They're simply trying to prevent fluid from building up in your lungs, which could lead to complications such as pneumonia. This means that you can actually use the restroom instead of the bedpan, which is something that you will certainly appreciate.

Before you leave the hospital, the physical therapist will show you how to get around with crutches, a walker or a wheelchair. Below-knee amputees probably won't need a wheelchair, unless they are very weak or have a heart condition. Above-knee amputees may require one early on, simply because the function and maneuverability of the knee is no longer there.

After you receive your prosthesis and complete your physical therapy (assuming there are no

other complicating health conditions), you should be able to return to your regular daily activities such as driving a car and going to work.

### How soon will I be able to start wearing a prosthesis?

Again, this depends on your particular condition. In the best case, you could be fitted with a temporary prosthesis while you are still in the hospital. Conversely, it could take a month or longer after your amputation. It all depends on how quickly the amputation heals. The process of determining when you are ready to be fitted for your prosthesis is covered in an article on page 34.

No two patients (and therefore no two amputations) are exactly alike, so it's hard to tell you exactly what your particular amputation experience will be like. Your experience may even vary depending on where you live, because typical treatment protocols tend to be different in various parts of the country. The important thing to know is that it is okay to ask questions of your medical team. Your doctor may have performed this procedure a hundred times, and your prosthetist may have fitted a hundred prosthetic limbs, but this is your first time as an amputee. You are entitled to understand what's happening to you.

### About the Author:

*Raymond Francis, CP, is a certified prosthetist with over 30 years experience. His patients have included amputees of all ages and activity levels ranging from older, less-active amputees to active-duty military.*



*He is the chief prosthetist for Ohio Willow Wood and works extensively on research and product development.*

# UPPER EXTREMITY

by Sean Toren

If you're about to undergo – or have recently undergone – amputation surgery, you're sure to have questions about everything from the kind of prosthesis you'll be fitted with to how long it will take you to get back to your normal, productive lifestyle. This article is designed to introduce you to such information, and hopefully to prepare, educate and motivate you to participate as actively as possible with the team of professionals who will be helping you.

## Prepare yourself with education

Amputations may be performed for a variety of reasons, including trauma caused by accidents, conditions present at birth, and disease (such as cancer, diabetes or vascular disease). No matter what the cause or level of your amputation, your attitude and motivation to participate in your therapy are essential ingredients to your successful rehabilitation.

One of the first things you can do is to prepare yourself as thoroughly as possible.

- Talk with your surgeon about the surgery and what you should expect.
- Speak with your physical or occupational therapist, who can give you preparatory strengthening exercises that can speed your recovery after surgery.
- Contact your prosthetist about prosthetic options. It's important that your prosthetist is certified, well acquainted with both myoelectric and body-powered systems, and familiar with new training, testing, and functional devices so that he or she can help determine the best system for you.
- Read or view any educational materials these professionals recommend.
- Finally, speak with fellow amputees – people who have been through similar experiences and can answer your questions.

## The surgery

Your surgery is the beginning of a "reconstructive plan" that includes your therapy and prosthetic fitting and is designed to help you recover successfully. First, a decision will be made concerning the level of your amputation, but your doctor will generally try to save as



much of the limb as possible.

There are various levels of amputation, each requiring different recovery therapy and prosthetic solutions:

- Transcarpal (through the hand)
- Wrist disarticulation (at the wrist)
- Transradial (through the forearm)
- Elbow disarticulation (at the elbow)
- Transhumeral (through the humerus)
- Shoulder disarticulation (at the shoulder)
- Forequarter (above the shoulder, removing the scapula and clavicle)

The surgery itself usually takes about an hour. Your surgeon will make an incision through skin, muscle, blood vessels, nerves, ligaments, and, if necessary, bone. An extra section of skin is retained and then sewn or stapled over the residual limb.

After the surgery, a protective dressing of gauze bandages will be applied to protect and gently compress the residual limb. There may be a drainage tube coming out of the bandages to rid the residual limb of excess body fluid. This tube will be removed after a few days, and the staples or sutures will be removed in about two weeks.

Once this initial dressing is changed, elastic bandages may be applied. These help control

swelling and prepare your limb for later prosthetic fitting.

### Recovering from the surgery—coping with change emotionally

The days and weeks right after the amputation surgery can be difficult for anyone. Losing a limb can cause disbelief or shock. You might feel angry about the change in your life, sad about the loss, uncertain about whether you'll be able to return to work or favorite activities, worried about your appearance. It's important to accept these emotions as normal and talk about them with family, friends, your professional team, and other amputees. Remember that other amputees have a good perspective on the process. Many have accepted their change, adapted to their situation emotionally and physically, and gone on to lead rich, active lives.

### Coping with change physically

You may have some pain after your surgery but your doctors and nurses will make sure you receive pain medication, most probably with a Patient Controlled Analgesia (PCA) that you can administer to yourself as needed.

### Phantom sensations and pain

Most new amputees experience phantom sensations such as itching, tingling, movement or even pain where the amputated limb used to be. These sensations are not generally indicative of other problems and usually disappear within a month.

### Preparing for your fitting

Within a day or two after surgery a physical or occupational therapist will prescribe therapy to help prepare you for your prosthesis. This therapy may include active exercises, isometric exercises, stretching, desensitization of your residual limb, and education regarding body positioning while resting to prevent your muscles and joints from becoming inflexible. You may also be taught how to wrap your residual limb with elastic bandages or tight "shrinker" socks to reduce swelling and shape the limb, preparing it for the prosthesis. It is



important that you understand your therapy and participate fully in it. A good attitude and the motivation to work hard will speed your recovery and make it as successful as possible.

### The prosthesis

Your upper-limb prosthesis may be a body-powered or an externally-powered myoelectric system.

Body-powered systems consist of a harness with cables attached to the prosthetic components. Contraction of large muscles can open

or close a prosthetic hand, or flex an elbow, by pulling on the cables.

Myoelectric systems are powered by batteries but actuated (turned on) through the use of your body's own electrical signals. In a myoelectric hand, for example, small sensors can read forearm muscles and know when to open or close the hand.

Both systems have their own advantages and disadvantages, depending on your needs. Body-powered systems are generally lighter and tougher, but require the use of muscle groups that must also perform other functions. Myoelectric devices are often closer cosmetically to a natural hand or arm and have the advantage of using the same remnant muscles, such as in the forearm, that originally were used to open and close a natural hand. Their disadvantages are that they can cost and weigh more than body-powered prostheses.

Talk with your prosthetist about which system – or combination of systems – will best fulfill your cosmetic and functional needs.

### The fitting

Fitting for the prosthesis will take place once your residual limb has healed, is no longer



tender or sensitive, and is no longer swollen. This usually takes from four to six weeks after the operation. Your prosthetist will discuss your functional and cosmetic needs, the level of your amputation and shape of your residual limb, your previous activity level and age, your range of motion, and available funding with you. Your doctor will then write a prescription based on your prosthetist's recommendation.

During your first visit the prosthetist will make a cast of your residual limb out of plaster so that a test socket can be made. The test socket is manufactured from a thermoplastic material and then fitted and refined during your following visits. It's important to obtain a well-fitting socket so that your prosthetic device can be attached without irritation, so this is a time to be patient and really work with your prosthetist to get the fit just right. Once the test socket has been refined, a "definitive," or final, socket will be made from lightweight thermoplastic or from a resin-matrix composite similar to fiberglass.

### Caring for your prosthesis

The normal life expectancy of a prosthesis is about five years, although, as with any mechanical device, the better you care for it the longer it's going to last. Your prosthetist will explain to you how to keep your prosthesis clean and well maintained. Weight gain or loss can affect the fit of your socket, too, and may necessitate a new fitting.

### A new beginning - using your new prosthesis

#### From an Amputee's Perspective

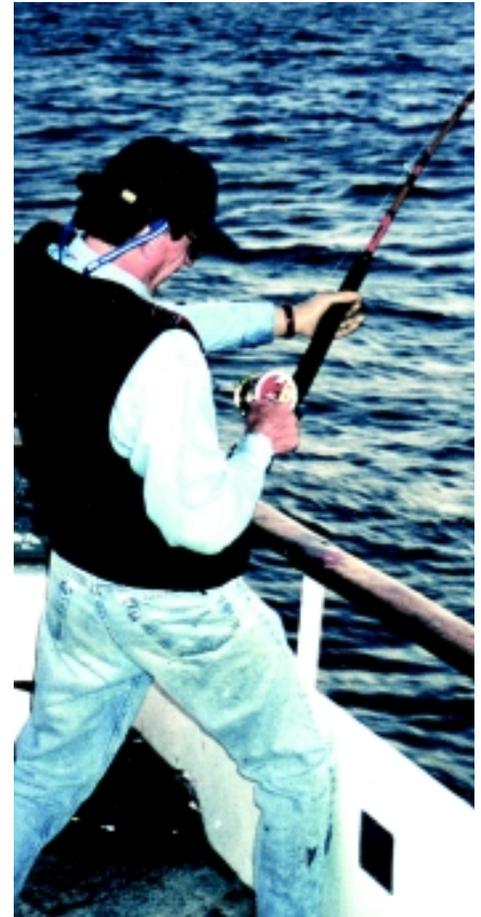
"Once you get your prosthesis it's just the beginning. Now you have to learn to use the thing," says Rick Schmierer, an upper-limb amputee for over 30 years. As a myoelectric technician at Otto Bock Health Care who now works every day repairing and maintaining sensitive myoelectric hands just like the one he uses, Rick knows about frustration – and conquering it. He argues that it all comes down to the right attitude and being motivated to work hard at learning to use your new "tool."

As you begin to use your prosthesis it is important to work closely with your occupational therapists. They'll help you to relearn such actions as brushing your teeth, popping the cap off a bottle, or driving your car.

But be patient; many new prosthesis wearers get depressed as they encounter difficulties using their devices. Rick says that this is natural once the excitement of receiving the new prosthesis wears off, but stresses that it's important to stay motivated and "think about what you can do, not about what you can't." He also encourages new amputees to talk with others. "Once you start networking with other amputees, you'll be amazed at what you can do," he says.

Your prosthetist will be able to put you in touch with amputee support groups. You may also want to contact the Amputee Coalition of America toll-free at 1-888 / AMP-KNOW or visit the Web site at [www.amputee-coalition.org](http://www.amputee-coalition.org)

*Rick Schmierer fighting the good fight while wearing his Otto Bock SensorHand.™*

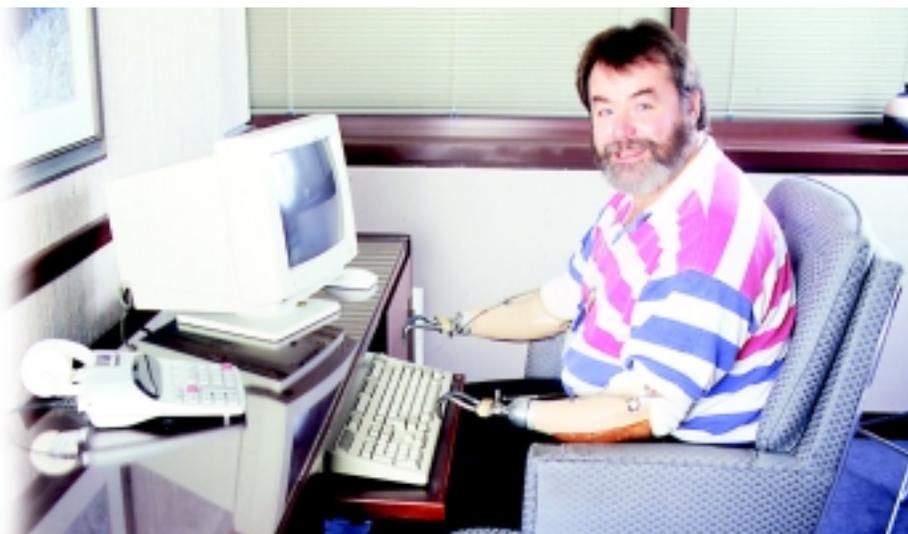


*Special thanks to Professional Services at Otto Bock Health Care, including Todd Anderson, CP, Michael Leach, CPO, Pat Prigge, CP, and Rick Schmierer.*

### About the Author:



*Sean Toren, an experienced freelance writer, is presently the writer and translator for Otto Bock Health Care.*



# QUESTIONS TO ASK YOUR SURGEON

by John W. Bowker, MD

Facing an amputation is one of the most daunting experiences that a person can have. Whether a result of sudden trauma or disease, the loss of part or all of a limb is something that none of us ever expects to encounter. Feelings of helplessness and hopelessness tend to engulf the individual as well as his or her family and friends. Although the latter two can offer vital emotional support,



nothing will help to clear away the fear arising from uncertainty and restore a modicum of hope as much as in-depth conversations with the surgeon and with other members of the team who will see the process of rehabilitation through to its conclusion.

For this process to be successful, the prospective amputee must insist on being a full member of the rehabilitation team, even prior to surgery. Initially, this is accomplished by becoming as well informed as possible about the amputation and its consequences. Many questions will occur to the person and significant others prior to the surgery. In the role of patient, the person has a right to have all of these questions answered promptly in a clear manner free of professional jargon.

Some of the points that should be discussed include:

## 1. The absolute need for amputation

You should be completely satisfied as to the necessity for removal of one of your limbs. The surgeon should be willing to review with you and others that you designate all pertinent information that has led to this decision, including the results of vascular studies. Because of the irreversible nature of amputation, you may feel more comfortable if you obtain a second opinion from a surgeon completely independent of the first. It is definitely to your advantage to become a well-informed consumer in this matter.

## 2. The level of amputation

The surgeon should be able to provide a clear reason why a certain level is chosen, especially if it is above the knee or elbow, because of the great difference in rehabilitation potential when the knee or elbow is lost. Ask what tests have been done or could be done to support the necessity for a high-level amputation. Again, a second opinion from an unrelated surgeon will also address this issue.

## 3. The sequence of events surrounding the amputation with a proposed "timetable"

Ask your surgeon to explain the significant milestones you should reach during your recovery. How soon will you start using a walker or crutches after surgery? How long will you be in the hospital? Will your health plan provide sufficient time in therapy to ensure that you will be able to care for yourself at home after discharge from the hospital prior to prosthetic fitting? Will you be transferred to a rehabilitation facility for this purpose? How often will the surgeon monitor your progress to determine your readiness for prosthetic fitting or will this be delegated to another physician? When should you expect to receive a prosthesis? What arrangement will be made for adequate gait training with the prosthesis? How often should you return for routine follow-up review of your status?

## 4. Meeting the other members of the rehabilitation team

As mentioned before, the amputee is the most important member of the team that will guide him or her to maximum potential. Ask your surgeon to arrange individual interviews with the coordinating rehabilitation nurse and the physical therapist or occupational therapist as appropriate. In the case of a lower-limb amputation, the physical therapist can evaluate your potential for walking with a prosthesis. There are many aspects to this including the presence of the knee, condition of the remaining lower limb and your general health and vitality. The occupational therapist can outline the function to be expected from use of an upper-limb prosthesis at the amputation level required. The prosthetist who will construct and fit your prosthetic limb will



present options in design, cosmesis and cost as well as suggest components appropriate for your activity level, vocation and avocations. The social worker or psychologist can provide help in coping with the emotional issues associated with the inevitable change in body image. In addition, a trained peer counselor, who has successfully passed through rehabilitation following a similar amputation, will provide living proof that a satisfactory lifestyle can be achieved. Ideally, if circumstances permit, these interviews should take place preoperatively or very early in the rehabilitation process.

## 5. Preserving the remaining lower limb

The surgeon should be questioned regarding measures that can be taken to prevent loss of the remaining foot and leg. Although statistical studies indicate that amputation of a lower limb for disease is followed by loss of the other within a few years, they do not take into account the preventive measures that can be taken. In the case of vascular disease, smoking cessation and prescribed exercise and diet may slow the process and encourage the formation of sufficient new

(collateral) vessels to ensure indefinite maintenance of limb circulation. In vascular disease, the incident that led directly to amputation may have been a minor injury to the foot that failed to heal. This can be prevented in the remaining foot by the consistent use of carefully-fitted shoes with a roomy toe box and custom-molded insoles that can be prescribed by your surgeon.

In the case of diabetes, there are also effective measures that can be taken to protect the remaining foot. Because most amputations in people with diabetes result from injury to a foot with decreased sensation, protection of the foot by well-fitted shoes is primary. Well-fitted shoes with appropriate inserts, if consistently worn, have been shown to be effective in preventing amputations in diabetic persons with specific risk factors. In fact, they have been so effective that the Medicare program provides partial reimbursement for them to all qualifying persons with diabetes on its rolls. Of course, barefoot walking and even the occasional use of other shoe designs is strongly discouraged. Other effective preventive measures include smoking cessation and tight long-term control of blood sugars. Although daily blood sugar measurements are of great importance in

the effective management of diabetes, the most reliable measure of long-term success is the quarterly level of glycohemoglobin, which reveals the average daily blood sugar over the previous three months. It should approximate 6 percent, which is equivalent to a safe average daily blood sugar level of 120 milligrams per deciliter of blood.

Getting complete, understandable answers to these and any other questions that occur to you is essential in building the trusting relationship necessary between the person about to undergo a major life-changing surgery and those who provide the surgical and rehabilitative care. The bond that develops will lead to the best possible outcome given the individual circumstances of each case. It is a two-way street requiring both an assertive, inquiring patient and caring, skilled team members who listen closely and respond in an open manner.



### About the Author:

*John Bowker, MD, is professor emeritus, Department of Orthopaedics and Rehab, University of Miami School of Medicine, Jackson Memorial Rehab Center.*



## SMALL PART FOR ABOVE-KNEE PROSTHESIS MAKES A BIG DIFFERENCE

*by John Rheinstein, CP*

"Some of the simplest tasks were difficult until I got a push button rotator," says Tal, a 27-year-old right above-knee amputee from New York City. A push button rotator (also known as a turntable) is a small component that can be installed between the top of a prosthetic knee and the socket. When the button is pushed, it allows the lower leg to swing to either side or completely around until the sole of the

prosthetic foot faces the ceiling. Then, when the prosthesis is brought back to its normal position the rotator locks the leg for walking.

With a rotator, Tal can now get in and out of a car more easily. By pushing the button through his cosmetic foam cover, he is able to swing his prosthetic leg out of the way as he sits down in the driver's seat. Since he uses a left foot gas pedal, the rotator also allows him to keep his prosthetic foot away from the car's regular gas pedal. It can also make long car or plane trips more comfortable by allowing for changes in position. "I use it everyday," says Tal, "for getting dressed and changing shoes." Without this device, he would have to take off his suction prosthesis and reapply it. Other amputees use the rotator for sitting on the ground or crossing one leg over the other when sitting on a chair.

A rotator can be built into a new prosthesis or installed on some existing ones. Discuss your needs with your doctor and prosthetist before getting your next prosthesis and, if there is enough space, it can be included in the design. Most insurance

companies will pay for it as long as your doctor prescribes it. There are three different models available and they all function in the same way

One problem may be length. If you have a long residual limb, then the addition of a rotator may cause the prosthetic knee to extend beyond the sound side knee when sitting down. If this happens, then you will need to decide if the increase in function from the rotator is worth the change in cosmetic appearance. A rotator adds a small amount of weight, which is usually not noticeable. Pushing the button requires adequate hand strength. Always make sure the prosthesis is locked back into walking position before standing up.

### About the Author:

*John Rheinstein is an ABC-certified prosthetist. He is the lower-extremity prosthetic specialist for Hanger Prosthetics & Orthotics in New York City, where he is engaged in clinical practice, research, and teaching. John can be reached by e-mail, jrheinstein@nyc.rr.com*

# DEALING WITH GRIEF AND DEPRESSION

by Omal Bani Saberi, LCSW, CCHT

# W

When a part of our body is lost, we experience a grieving process much like a death. In her book *On Death and Dying*, Dr. Elizabeth Kubler-Ross has outlined five stages of the grieving process that occur in conjunction with dying. These stages, in the context of limb loss, are:

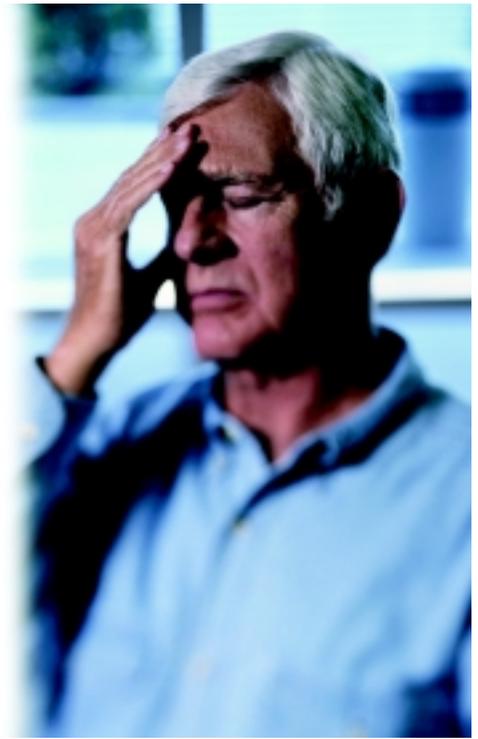
- 1. Denial and Isolation.** "This is impossible. It's not really happening! I feel nothing at all."
- 2. Anger.** "Why is this happening to me? I'm enraged! God is unjust."
- 3. Bargaining.** "If I promise to do such and such, maybe I'll get my old life back."
- 4. Depression.** "I feel hopeless. Everything is beyond my control. Why bother trying? I give up."
- 5. Acceptance.** I don't like it, but the amputation is a reality. I'll find ways to make the best of it and go on."

The cycle of grief does not flow easily. Emotional recovery like physical recovery is based on your own timetable and other factors. These include: age, gender, circumstances of your limb loss (accident, disease, birth), how you coped with problems in your life before your limb loss, support or lack of support from family or friends, cultural values and norms, and socioeconomic factors.

The new amputee may experience feelings of depression that are difficult to ward off. What are these feelings and how can you work through them?

## Signs & Symptoms of Depression

- Loss of appetite, changes in eating patterns
- Lack of energy
- Sleeplessness or sleeping more than usual
- Poor concentration
- Diminished interest in enjoyable activities
- Loss of interest in sex
- Social withdrawal
- Feelings of hopelessness, worthlessness, or inappropriate guilt
- Emotions that are flat – expressed robotically rather than with feeling



## SURVIVING DEPRESSION

Following are some suggestions for overcoming your depression, physically, emotionally, mentally, and spiritually.

### PHYSICALLY

- 1. Get your rest.** Each day get out of bed, get dressed, and, if possible, go out of the house.
- 2. Make sure you eat well** – not too many sweets. Foods with sugar will give you quick bursts of energy then quickly let you down, taking you deeper into depression.
- 3. Get involved in physical and recreational activities that do not cause you pain.** Exercise and gentle movement will release endorphins to help decrease depression.
- 4. Practice deep breathing.** This will help relax muscles, decrease pain, and relax and focus the mind.
- 5. Decrease alcoholic beverage intake.** Alcohol is a depressant. Eliminate other drugs that you use to self-medicate. If



using prescription drugs, make sure you take them when prescribed.

**6. Accentuate your best features; don't focus on the loss.** For example, if you have beautiful skin or eyes, a bright smile, a terrific figure or a great personality, this is the time to value your assets.

## EMOTIONALLY

**1. You are not alone.**

**2. You are not to blame.** It is important that you feel the anger, because if you don't, it will lead to depression.

**3. Write letters and don't mail them.** Journal your feelings.

**4. Increase contact with supportive family and friends.**

**5. Assert yourself and communicate clearly.** Tell those around you what you need and don't need. For example, you may need to expend less energy this year; conserve your energy. Go to a movie or rent a video, especially if the weather is harsh.

**6. Tell your loved ones you are experiencing grief and talk about your loss together.** This gives your loved ones the chance to express their feelings, since they, too, have to adjust to your loss. So don't skirt around the issue, walk on eggshells or ignore the problem. Be honest and talk it out. This will give you and yours a greater chance to heal and adjust.

**7. Remember, people want to help but often don't know what to do to support you.** So ask, ask, ask! You can remain independent – but let go of the controls for now. Allow others to give to you, so you can replenish your energy.

**8. Explore the potential benefits of meditation, guided imagery and hypnotherapy.**

**9. Contact a support group.** If there isn't one in your area, contact the ACA office toll-free at 1-888/AMP-KNOW for information and help.

**10. Laughter is a healer of depression, so add humor;** make light of something that is serious, and laugh at yourself.

**11. Get professional help if the depression becomes overwhelming and no small changes are occurring.** Everyone needs help at some point in his or her life. Be a positive statistic. You are worth it. If finances are a problem, call your local mental health office or the ACA at 1-888/AMP-KNOW for information on financial resources. (See articles on funding beginning on page 84.)

**12. Most importantly, know that these feelings will lessen over time;** however, for now, get support!

## MENTALLY

**1. Commit yourself to work with the medical staff, physicians, nurses, occupational and physical therapists, and prosthetists, even when you don't want to.**

**2. Do not make big decisions such as beginning or ending a relationship, or buying or selling a house or car, when you are depressed.** You may regret this later.

**3. Go to a psychiatrist for evaluation and medication if necessary.**

**4. Seek alternative medicine, massage, acupressure, acupuncture and hypnotherapy for pain management, phantom pain, sleeplessness, anxiety and depression.**

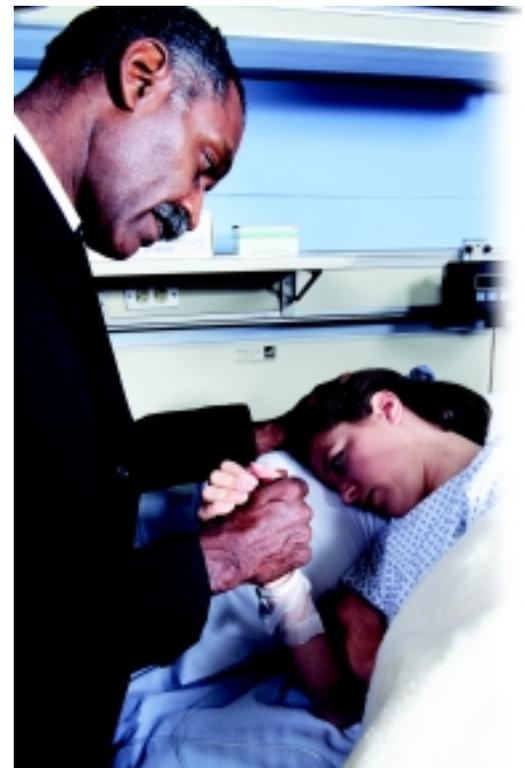
**5. Replace negative self-talk about your body and life with positive cognitive messages.**

## SPIRITUALLY

**1. Forgive yourself; don't judge.** Dr. Harold H. Bloomfield, co-author of *How to Heal Depression*, states, "The primary reason to forgive is for your peace of mind and the quality of all your future relationships. That's what we do when we forgive – let go of the imaginary (but painful) control of the way we think things could be, and we untie ourselves from the burden of judging the way they are."

**2. Learn to redefine yourself.**

- Forgiveness. Keep your dreams and create a new definition of success.
- Accept support from loved ones while remaining independent.
- Make new rituals/memories thus creating



hope for the present and future. A part of you is only physically gone or altered; the core of you is still the same. Make goals and objectives for the future and start small.

- If your religion or spirituality is important to you, become more involved with it.

## Summary

Amputation is an enormous loss and learning to adjust is a process that takes time – so be gentle with yourself. Try not to isolate yourself or withdraw from people; use your experiences to build new memories and start new traditions to reach your goals. Sure, there will be adjustments for your disability along the road to success – but it is still your path. Who you are has not changed. Always remember, you are much more than your physical experience.

## About the Author:



*Omali Bani Saberi is an above-knee bilateral amputee. She is a licensed clinical social worker (LCSW) and a certified clinical hypnotherapist (CCHT) with Master's Degrees*

*in Social Work and Counseling Psychology. Currently, she is in private practice, providing mental health services, including counseling and psychotherapy. You may reach her by e-mail at [OBSPEACE@cs.com](mailto:OBSPEACE@cs.com)*

## Resources

### National Mental Health Information Center

1020 Prince Street  
Alexandria, VA 23314-2971  
800/969-6642

(Or contact your county mental health association)

### *How to Heal Depression*

Harold H. Bloomfield, MD, and Peter McWilliams

### *Coping with Limb Loss*

Ellen Winchell, PhD  
(Available through ACA – 1-888/AMP-KNOW)

### *On Death and Dying*

Dr. Elizabeth Kubler-Ross  
(New York: MacMillan Publishing, 1969)



# FINDING A QUALIFIED THERAPIST

## What's in a Name?

by Omali Bani Saberi, LCSW, CCHT

### Definitions and Degree Criteria

Each state may have different education criteria or different names for mental health professionals. The following information is based on California's definition. If you need assistance in the type of questions to ask to help you make a better-informed decision, please do not hesitate to e-mail me at [OBSPEACE@cs.com](mailto:OBSPEACE@cs.com)

- **Psychologist, PhD** – Provides counseling, psychotherapy and psychological testing. Most clinicians take insurance and Medicare.

- **Psychiatrist, MD** – A medical doctor who provides medication assessment. Some will provide counseling, psychotherapy and psychiatric testing; however, a psychiatrist's primary functions are medication assessment and evaluation. Most doctors accept insurance.

- **Licensed Clinical Social Worker (LCW, LCSW)** – Master's degrees with 3,200 hours of written and oral exams toward licensure. Provides mental health services, counseling, psychotherapy and some testing.

- **Marriage, Family Counselor (MFT, MFCC)** – Master's degrees in counseling. Provides counseling and psychotherapy for relationship issues. May accept some insurance.

### How do I get help?

1. Ask a friend or colleague you trust.
2. Call your insurance provider and get three names of professionals in your area who specialize in treating your particular problem, e.g., depression, anxiety, etc.
3. Speak with your physician.
4. Speak with your prosthetist.
5. Call your county mental health association and ask for three clinicians in your area.

- National Association of Social Workers (NASW)
- American Psychological Association (APA)
- American Medical Board (AMA)
- Call the ACA office toll-free (1-888/AMP-KNOW)

# PAIN

## *What to expect*

by ACA Staff Writers

**P**reoperative pain  
Significant pain may be experienced in the preoperative period due to gangrene, vascular disease, a tumor, infection or trauma, and may continue right up to the moment of surgery.

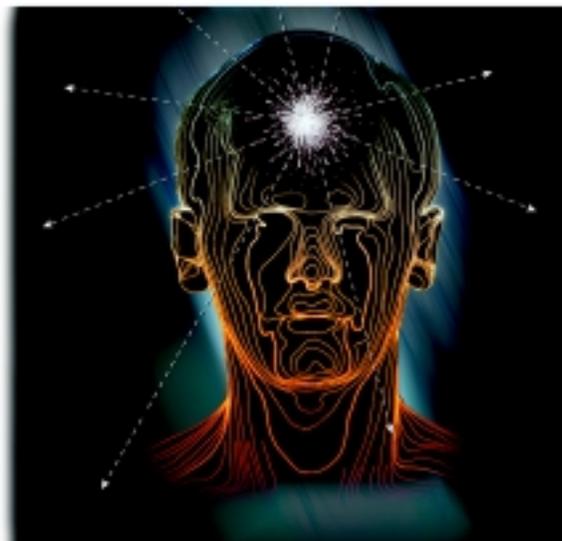
This pain and anxiety relief may require narcotic and non-narcotic pain medications, anti-anxiety medications, and other techniques that should be familiar to the physician, surgeon, and anesthesiologist providing care. This is not a time to suffer in silence. This is a time to ask for, and, if necessary, demand adequate relief of pain and anxiety. When a person experiences pain, the chemicals produced by the brain to deal with pain and stress are used at a rapid rate. Once depleted, they are not available in the postoperative period to assist with recovery. Going to the operating room for an amputation in a calm, relatively pain-free state is much more conducive to an easy recovery than doing so after days or weeks of severe, unrelieved pain and anxiety. In addition, medical literature increasingly suggests that excellent pain relief (analgesia) in the preoperative period may result in a decrease of ongoing postoperative pain.

### Intraoperative pain

Amputation is, unfortunately, a painful surgical procedure. Every type of tissue in the limb is severed during the amputation, including skin, muscle, bone, tendon, nerve, and blood vessels. Every one of these tissues has abundant nerve endings and all can hurt during and after amputation.

When available, anesthesia has been used for amputations since it was invented over 100 years ago. Usually, a type of general anesthetic that puts patients to sleep is used, rendering the patient unaware of the amputation and its painful nature. Recently, several studies have revealed that interrupting the painful nerve impulses before they reach the brain may actually decrease the probability of long-term post-amputation pain.

For many years, medical science has known that injecting Novocaine, cocaine, procaine,



marcaine, or lidocaine in or around the nerves can prevent pain impulses from reaching the brain. The anesthesia can be injected into either the nerve or nerve sheath itself, the spinal cord (spinal analgesia), the area just outside the spinal cord (epidural analgesia) or a combination of these places. There is often confusion about the difference between spinal and epidural anesthesia. A spinal involves injection of the medication in the space right next to the spinal cord (between the spinal cord and the dura – the cord's covering). It is usually a one-time shot, and a catheter is rarely left in for repeat injections. An epidural involves injection of the medication in the epidural space (outside of the dura). With this technique, a catheter is usually left in place for repeat injections over longer periods. Occasionally the epidural catheter is left in place for several days to give postoperative pain relief.

The anesthesiologist often employs a combination of techniques. The patient about to undergo an amputation should always discuss in detail with the anesthesiologist and surgeon the techniques and anesthetics they plan to use during surgery. This discussion should focus on issues of safety, risks, and pain relief during and after the surgery. There may be excellent reasons that one anesthetic technique is recommended over another. This is the time when an informed consumer is his or her own best advocate.

### Immediate postoperative pain

During the first 72 hours following an amputation, swelling occurs, tissues are stretched,





severed nerves are not sending normal impulses to the spinal cord, and many other new realities are being experienced. Tension, fear, anger and denial may be producing a strong emotional “stew” for the new amputee. Physically, this is the time that patients will experience the most severe pain. There is clear evidence that adequate relief of pain and anxiety during this chaotic period is extremely important in preventing long-term postoperative pain.

It is important to consider various types of pain relief in the postoperative period, including narcotic and non-narcotic analgesic medications, anti-anxiety medications, and anti-depressants. Narcotic pain medications like morphine, Demerol and Fentanyl have been used for years to relieve severe pain. The use of these strong pain medications has been the cornerstone of relieving pain after amputation.

### Patient controlled analgesia

One administration technique is Patient Controlled Analgesia. This means that the patient actually controls the timing of the doses of pain medication. To do this, a small electric pump containing a syringe of pain medication is attached to a switch. When the patient pushes a button, the pump gives a premeasured dose of the pain medicine. The doctor determines how much medicine is safe and how often it can be

given. The analgesia is then given through an intravenous tube so that it enters the blood stream immediately. A small amount can be given as often as every six to 10 minutes. This has several benefits compared to the traditional injection in the muscle. It takes effect much more quickly, and there is less risk of over-sedating the patient. This method also gives the patient more control of his or her medication and the quick onset helps to relieve the anxiety of waiting for medication delivered in other ways.

In addition to narcotic pain medications, less potent non-narcotic analgesics include aspirin, acetaminophen, ibuprofen, and other nonsteroidal anti-inflammatory drugs. All are useful when properly administered and should be used with guidance from a surgeon and anesthesiologist. Other medications that can be helpful include tranquilizers such as Vistaril, anti-depressants such as Elavil, and anti-seizure medications such as Neurontin.

### First six weeks post-amputation

During the first six weeks after amputation, many changes are occurring rapidly. Most of them are positive changes with decrease of pain and swelling and increase of mobility and accommodation to the physical reality of amputation; however, there are many real problems during this period, physical as well as emotional.

There is typically a decreasing need for pain medication, but there may be an increased need for medicine to help with sleep or to deal with anxiety or depression. There is change in physical activity and the need to learn new methods of dealing with formerly routine tasks. Coming home from the hospital may be highly desired, but also feared. It requires increased physical efforts as well as the emotional challenge of dealing with old relationships and demands despite a new physical reality.

Fears of dependency, inadequacy, and rejection may be the most important but unspoken part of the new amputee’s thoughts. Questions about the ability to work or maintain physical independence may demand a share of the emotional resources now dedicated to learning to walk or to bathe independently.

While the physical pain may decrease dramatically, the emotional turmoil may spiral

uncontrollably during the six or eight weeks after an amputation. This stress may significantly affect the amputee’s ability and willingness to deal with the remaining physical pain. The chemicals in the brain that help alleviate pain may be expended by this time, increasing the amputee’s pain, anxiety, and stress.

### Phantom pain

Phantom pain is real; however, only a small percentage of amputees have severe problems with phantom pain. For many, the pain occurs in very short episodes, passes quickly, occurs less as time goes on, and, in general, is very manageable. Much is still unknown about phantom sensations in absent limbs and phantom pain, but medical science is learning more about its origins and treatments.

Some patients say the pain they felt in their limbs immediately before amputation persists as a kind of pain memory. For example, soldiers who had grenades explode in their hands reported that their phantom hand is in a fixed position, clenching the grenade, ready to toss it. The pain in the hand is excruciating - the same they felt the instant the grenade exploded.

A woman in England suffered severe frostbite on her thumb as a child. Gangrene developed and the thumb had to be amputated. Now, 50





years later, she reports having chilblains (a frost-like pain due to cold weather) in her thumb when the weather turns cold.

A girl born without forearms experienced phantom hands six inches below her residual arms. She reported using her phantom fingers to calculate arithmetic problems.

Today, thousands of such stories have the medical profession acknowledging that what these people feel is real - and often debilitating. Many doctors even specialize in phantom pain and sensation. Their hope is that research will help thousands of people around the world enjoy pain-free lives.

### Relief for phantom pain

Despite intense research in this area, there is still much to be learned about the physiology of the nervous system and how to treat phantom pain. Therapies include medications and biofeedback, electrical nerve stimulation, massage, heat, cold, compression, acupuncture and acupressure, cranial sacral therapy, and touch treatment therapy. Just as the amount of pain people feel differs between patients, so do treatment results. What works for one person may not be effective for another.

### Back pain

Researchers are currently investigating the different types of pain and sensations following amputation. Studies have indicated that

painless phantom limb sensations were quite common, and occurred more frequently than phantom limb pain. Residual limb pain and back pain were also common following amputation.

In one recent study, back pain was surprisingly rated as more bothersome than phantom limb pain or residual limb pain. Back pain was significantly more common in people with above-knee amputations. Research also suggests that back pain following lower-extremity amputation is likely to be overlooked but is an important pain problem, warranting additional clinical attention and study.

### Conclusion

All of the recent studies also support the importance of looking at pain as a multidimensional rather than a one-dimensional construct. This means that the impact pain has on an



individual's life is influenced by its frequency, duration, intensity, bothersomeness, and whether it is episodic or continual. All of these different factors make pain very difficult to measure and study accurately.

Unfortunately, there are no magic treatments to fully eliminate pain; however, physicians are emphasizing prevention with symmetrical gait training, proper back care, good sitting posture, and good lifting habits.

For now, until research offers improved pain treatment, it is a matter of managing the problem rather than curing it. The important thing is to educate patients in the options available to them so that they can restore their functions and attain a better quality of life.

For more information on the various therapies to combat amputation pain, contact the ACA office toll-free at 1-888/AMP-KNOW (267-5669).

*Sources: Information compiled from inMotion magazine articles, NLLIC information specialists, and Dr. Doug Smith, ACA medical director.*



# THE VALUE OF PEER CONTACT

## *A Source of Emotional Support and Information for Amputees and Their Families*

by *inMotion Staff Writers*

**W**hen someone wakes up in the hospital after having a limb amputated or discovers that their child has been born with a congenital limb deficiency, he or she might experience shock, anger, denial, or even depression. Life might no longer seem worth living. Questions might bombard the person's mind: "How can anyone, especially someone of the opposite sex, stand to look at me?" "How will my child play baseball or football?" "How can I make a living without arms or legs?"

It is a time of panic and reflection. New amputees and parents of children with limb deficiencies know that family and friends really cannot understand their feelings no matter how much they would like to. And although doctors, social workers, and therapists might have treated numerous amputees before, they really cannot understand what it is like to lose a limb unless they have gone through it themselves.

That's why peer support is so important.

"Nothing brings more hope to a new amputee about life after amputation than a trained peer contact," says social worker Cheryl Bias. "I have observed the value of a well-matched, trained peer contact, and I have also seen a new amputee's eyes glaze over when I, a nonamputee, have talked with them. This reaction is markedly different when compared with the patient's attentiveness to someone who is living with amputation day to day."

Only a fellow amputee can convince the new amputee that feeling discouraged is natural, but that limb differences do not define the person. Though the limb-deficient person might have to learn to do things differently, he or she is still the same person. The veteran amputee can show by his or her presence that there is life and opportunity after recovery. If he or she has a family, it will demonstrate that a person with a limb deficiency can have a social life. If he or she is working, it will demonstrate that people with limb differences can work and make a living — that life goes on. And if the veteran amputee is an athlete, artist, archer, or architect, it might help drive home the message that almost nothing is beyond the reach of people merely because of limb differences.

"Seeing someone who has a similar amputation but is active and doing well in life can bring so much hope to the new amputee," says Liz Zemke, a registered nurse and an ACA regional

representative.

Five years ago, when Zemke's right leg was amputated at the knee, there was no amputee peer visitor program in place for her to reach out to for comfort and direction. "It would have made all the difference in my recovery if I had had the kind of support, understanding, and information that only amputees can provide to each other," she says.

Peer supporters can also demonstrate some of the practical aspects of being an amputee, such as how to perform daily activities like driving and cooking, how to use a prosthesis, how to get involved in sports or recreational activities, how to deal with strains in personal relationships, and how to help family members and friends cope.

Seeing someone who has survived and thrived regardless of a limb deficiency gives the new amputee or family member new hope that life is still full of opportunities. The inspiration from such an example is worth thousands of words from those who have never been tried by the fire themselves.

"I can't emphasize enough the importance of being able to link with someone who has been there, done that," says Becky Bruce, ACA outreach information specialist.

A left below-knee and right Syme amputee, who also has diabetes, Bruce has endured repeated operations and hospitalizations. Through it all, she has retained a zany sense of humor and a unique perspective on life. "At first, I didn't go to a support group; I felt alienated. But after I had my Syme procedure, I joined a group, and I felt an instant camaraderie with the people there that I couldn't get anywhere else."

### The importance of training

The Amputee Coalition of America (ACA) and the National Limb Loss Information Center (NLLIC) recognize the benefits of peer contact. That is why the National Peer Network was established — to help people with limb differences and their families make contact with those who have had similar experiences.

Although some amputees might be naturally good as peer supporters, the ACA and the NLLIC, along with many others, strongly support peer training.

"I believe it is very important to train peer visitors," says Marianne Rankin, a member of the



ACA board of directors and a bilateral below-knee amputee. "Peer training teaches you that your role is to complement the individual's medical care but not compete with or replace medical professionals. It teaches you how to present yourself in a professional manner while ensuring that you maintain sensitivity toward the patient's emotions and acknowledge the reality of the situation. It also teaches communication techniques to promote emotional recovery and empathetic listening."

Untrained peer visitors are more likely than trained ones to unwittingly cause harm to those they are trying to help. Over-identifying with negative emotions, attempting to solve the problems of others, offering one-size-fits-all solutions, giving medical advice, and criticizing healthcare professionals can hinder rather than help individuals in crisis situations. And these are just a few of the errors that untrained peers can make.

Experienced amputees who have successfully made the transition to their new life are the best candidates for fulfilling the job of a peer visitor. Good training – with a brief orientation to best practices for peers, guidelines to follow, and resources available – helps peers develop the objectivity, listening skills, and appropriate techniques that will increase the chance for successful encounters.

The ACA provides such training through the ACA Peer Training Program, which includes presentations, discussions, and role-playing to prepare individuals to communicate effectively and complement, rather than hinder, medical care. Generally, this is done in a six-hour workshop that deals with the stages of grief and loss, communication techniques, coping skills, and available resources.

Twelve peer training seminars are offered each year across the country to maintain a large pool of trained peers. This training and certification helps assure callers of qualified, timely follow-up, assistance, and support. In addition, the ACA works collaboratively with support groups to provide peer training, experienced trainers, training manuals, possible funding sources, and educational materials.

"ACA-certified peer training not only provides a peer visitor with the basic skills to conduct a peer visit, but also provides an environment for

individuals to network with others who have the same interest in being a peer visitor," explains Leslie Duncan, NLLIC program manager for education and research. "I believe that communication, support, and the sharing of ideas and experiences between trained peer visitors are key components in the success of the National Peer Network."

## Finding a peer contact or support group

Even after people with limb deficiencies or their families make the decision to speak to a peer

visitor, they might find it difficult to locate one in their geographic area on their own.

Through the ACA National Peer Network's ever-growing database of trained and experienced amputee peers, those with limb deficiencies or their families can be put in touch with someone who has offered to help. The ACA will also attempt to match them with someone in the Network of similar age and the same gender, who has gone through a similar limb loss.

The Network is part of an information hotline where 24-hour contact is available via phone, fax, e-mail, and surface mail. Those in need of



## YOUNG AMPUTEE GIVES KENNEDY HOPE AFTER AMPUTATION

*by inMotion Staff Writers*

Tragedy can strike anyone. Money, fame, and political power are no guarantees of safety. And everyone sometimes needs support.

Edward "Ted" Kennedy Jr. – an heir to the Kennedy dynasty – lost a leg to bone cancer in 1973 at the age of 12. Now 40, Ted Jr., the son of Sen. Edward M. Kennedy, practices health and disability law at Wiggin & Dana, a law firm in Connecticut.

"When I was 12-years-old," Ted Jr. says, "I discovered a lump right below my kneecap. When I told my parents about it they took me to a pediatrician who said it was probably just a calcium deposit and to soak it in Epsom salts for a few weeks and come back."

But Ted Jr. knew something was drastically

wrong. Skateboarding one afternoon, he fell and hit his leg on a curb. "The pain lasted for an abnormal period of time, and I told my parents we'd better check this thing out," he says. The examination revealed a tumor, and a biopsy revealed a malignancy. His leg was amputated above the knee the very next day.

"I remember my dad coming into my room and telling me that I was going to lose part of my leg," Ted Jr. recalls. "I was petrified and horrified at the thought. I remember thinking that living life with one leg was worse than not living at all. I really honestly did."

Recalling the power of peer support when he first lost his leg, Kennedy says, "A young boy with an artificial leg came into my hospital room for a visit. I don't remember what he said. I don't remember what he looked like. I was so transfixed on his prosthesis as he walked into my room. All he had to do was show me that he could walk into and out of my room. That's all I needed to give me the personal strength to go on."

Kennedy was the keynote speaker at the 1999 ACA Annual Conference in Reno, Nevada. He shared his experiences and offered a few words of advice to parents of children with disabilities. "Encourage the child to feel comfortable in expressing him or herself. Having an amputation is a traumatic thing. Today, we know there's a lot of anger, frustration, and depression in many cases, pent up inside. It's important that parents address the emotional rehabilitation of the child and not gloss over the situation and pretend that nothing is wrong."

assistance might receive help by talking to someone on the ACA hotline, by arranging a visit or phone conversation with an individual, through letters, fax, or e-mail, or by attending a support group meeting.

Incoming requests for information or assistance are documented and forwarded to the appropriate ACA information specialists for processing. The ACA currently has 12 volunteer regional representatives who are experienced support group leaders. These individuals are located nationwide and communicate with groups in regions varying in size from three to five surrounding states. Regional representatives have knowledge of new groups forming in their region and special group activities (e.g., sports, social,

and educational activities) and can readily identify special-interest support groups on request. Information specialists, the outreach information specialist, and regional representatives offer referrals to amputee support groups that are as close as possible to the inquirer's city.

Becky Bruce notes that some people who call the ACA are disappointed when they find that there is not a support group within a 50-mile radius of their home. "Start one yourself," she advises. "ACA can help you. Many people don't understand what's involved. It's not just a group of people crying and telling their story; some people can't open up that quickly. Sometimes you can go to a meeting and not say anything. You can listen and learn."

The ACA and the NLLIC are available to help amputees find peer visitors or support groups in their area, to train peer visitors, to help establish support groups, and to help show those with limb differences and their families that their lives are not over — that they have merely turned a new page where new opportunities await.

*Contact the ACA National Peer Network to find a peer support person or support group. Call toll-free 1-888/AMP-KNOW (267-5669) or write: The Amputee Coalition of America, National Limb Loss Information Center, 900 E. Hill Avenue, Suite 285, Knoxville, TN 37915-2568. E-mail: [NPNinfo@amputee-coalition.org](mailto:NPNinfo@amputee-coalition.org)*



*Alex Locust (right) and a friend*

## YOUTHS REACH OUT TO HELP OTHERS

*by Rick Bowers*

Ten-year-old Alex Locust of Harrisburg, Pennsylvania, and 17-year-old Craig Pratka of Yaphank, New York, recently went out of their way to help other young amputees deal with their fears, concerns and lack of information about amputation.

Alex, who was born with only one leg, believes that one person can make a difference in the world, and he has set out to prove it. He swims every year in an event to raise money for kids with cancer and recently volunteered to visit a 2-year-old amputee, who had lost her leg in a lawnmower accident.

"Katie had already been through a lot and she is just 2 years old," Alex says. "I wanted to talk to her so that she would know that she is not the only kid who has to put her leg on in the morning and then take it off at night. I wanted to be her friend."

Alex says the visit he and his mother, Lori,

made to Katie's house went great. "Katie was very shy in the beginning but later on she wanted to do everything. The family was curious about my leg, so I showed it to them and explained a little bit about how it works. We talked about how I was born this way and why I needed to use my 'helper leg.' We also told the family about ASPIRE (an amputee support group for youths).

"Her mother told my mom that it was good to see someone older than Katie do the things that I am able to do. We only live about 15 minutes apart, and I just want Katie to know I am here as she gets older," Alex says, adding that he plans to keep in touch with the whole family.

"I am very, very proud of Alex," Lori says. "When Alex was born, we did not actively seek out support from others in our situation. We felt the need to focus on Alex and his needs and, to be honest, I did not put a lot of stock in support groups. I felt that if I attended such meetings, I would be admitting that there was 'something wrong' with Alex, and I have never felt that way. I see now what a difference that connecting with people in similar situations can make and, hopefully, we will be able to continue this in the future."

Craig, whose right leg was amputated above the knee a few years ago after an accident, was recently told about a 15-year-old named Luke who had also had his right leg amputated above the knee as the result of an accident. Luke had contacted the ACA about talking with other amputees, and Craig readily volunteered to call him. "I am always willing to share my story with new amputees and answer questions, no matter how ridiculous they may seem

to the person asking," he says.

Craig enjoys running and skiing and has won several medals in sports. "Since Luke showed interest in living a normal life and athletics," Craig says, "I recommended he look into getting a hydraulic knee and Flex-Foot combination, which is what I presently have. Also, because he was about to start driving, I explained to him how to drive a car with his left leg and went over the basics like taking showers, how high the socket goes up, swimming, phantom pains and girls."

Craig and Alex both believe that their efforts were helpful, and they both intend to continue giving peer support to those in need.

"At the end of the phone call," Craig says, "Luke seemed more excited about getting a new leg and most of his questions were answered."

Alex and Craig are giving their young peers something that their parents, friends and healthcare workers cannot — living proof that they, too, can live normal and happy lives despite the loss of a limb. And that's what peer support is all about.



*Craig Pratka*

# POST-OP PROSTHESES OFFER BENEFITS AFTER AMPUTATION SURGERY

by John Rheinstein, CP

**P**ostoperative prosthetic limbs can help speed recovery time, protect the wound from trauma, and reduce pain and swelling after amputation surgery. These types of prostheses are known as Immediate Post-Op Prostheses (IPOPs). They are applied in the operating room or in the early days following surgery. Without an IPOP, patients usually wait until the surgical wound heals before getting their first prosthesis. During the healing period, which can vary from three to 12 weeks, patients generally move about in a wheelchair or with crutches or a walker. The longer the waiting period, the greater the risk that patients may experience limb weakness, body deconditioning, joint stiffness, or injury to the residual limb from falling while trying to move about on one leg. By getting an IPOP, many patients can begin their rehabilitation sooner, more safely and have less uncertainty about their future.

There are two basic types of IPOPs: hand-molded and prefabricated. With the first type, a prosthetic socket is hand-molded from plaster bandages. A foot and pylon may be attached, allowing for controlled partial weight bearing. These plaster sockets are nonadjustable and nonremovable. If the doctor needs to look at the residual limb, the plaster socket must be cut off and reapplied. In addition, the cast needs to be reconstructed at regular intervals as the patient's limb changes.

A Removable Rigid Dressing (RRD) is another type of hand-molded socket made from plaster. It can be removed and adjusted by adding socks - but like the IPOP, it must be reconstructed as the patient's limb changes. The RRD is, however, nonweight bearing.

Prefabricated IPOPs are made from plastic in standard sizes. They are adjustable as a patient's limb changes and are easily removable. This allows the doctor and the rehab team to assess a patient's progress on a daily basis and to temporarily discontinue the IPOP if complications develop. They are more expensive than the hand-molded IPOPs and patients with very long or irregularly shaped limbs will not fit into them.



As with all medical treatments, there are both benefits and risks of possible side effects with the use of IPOPs. Patients will have different results and experiences depending on their own personal and medical circumstances and the protocols of the medical center where they are treated. Research on outcomes with plastic IPOPs is now underway.

The benefits and risks discussed below are based on clinical experience, input from patients, and past research on handmade plaster IPOPs.



## Benefits of IPOPs

In general, an IPOP can:

**Control swelling** – By applying gentle pressure to a patient's residual limb, an IPOP can minimize swelling. This helps the healing process and shapes the limb, making the eventual custom-made prosthesis easier to fit.

**Reduce pain** – By controlling swelling, pain is often reduced. Initial research also indicates that early prosthetic use may reduce the occurrence and severity of phantom sensations.

**Improve balance and safety during transfers** - Current research shows a dramatic reduction in the number of falls with the use of an IPOP. This is especially important for people who are weak or have other medical complications.

**Protect the wound site from trauma** – The IPOP forms a protective shell around the limb. If a patient falls or rolls around in bed, the IPOP can help prevent additional injury to the wound.

**Prevent joint contractures and loss of muscle strength** – By allowing amputees to stand and to gradually begin using their legs, an IPOP can prevent or reduce stiffness and weakness.

**Speed up the training and adjustment period** – Earlier use of a prosthesis often results in a faster transition to a temporary or definitive prosthesis as patients develop earlier tolerance to weight bearing.

**Reduce the length of hospital stay** – By enabling patients to be more functional, an IPOP can help them return to their homes or workplaces sooner, especially if wheelchair accessibility is a problem.

**Provide psychological benefits** – Patients learn early what it feels like to wear a prosthesis and can, thus, focus more on their rehabilitation than on their missing limb. This can be very positive as long as it does not delay

the process of accepting the loss of their limb.

## Risks and side effects of IPOPs

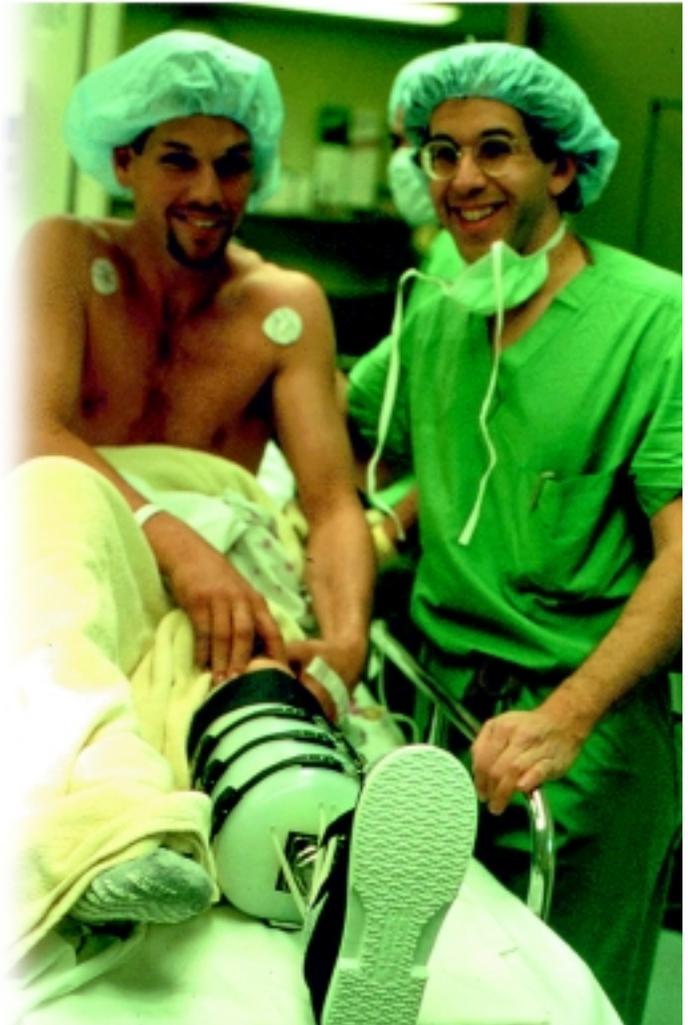
Not all patients are good candidates for IPOPs. It is up to the physician and the rehab team to decide if the benefits outweigh the risks. Side effects can be avoided or minimized with attentive care by a well-trained rehab team. Damage to the wound can occur from excessive weight bearing too soon after amputation. To use an IPOP correctly, the patient must be able to limit the amount of weight he or she applies to it. Complications can also occur whether or not an IPOP is used because of underlying disease. For example, some patients may develop infected or nonhealing surgical wounds. In these patients, IPOP use is discontinued while the problem is being resolved.

## Summary

IPOPs can be of significant benefit to new amputees if they are used correctly under the supervision of a trained rehabilitation team. A doctor and prosthetist should assess which type of prosthesis is best for each individual patient.

## What you can do

Patients should be aware that an IPOP is an option so that they can discuss it with their doctor and rehabilitation team before amputation. Most insurance plans will cover the cost of these devices if prescribed by a physician. Further information can be obtained from your doctor or prosthetist.



## About the Author:



*John Rheinstein, an ABC-certified prosthetist, is the lower-extremity prosthetic specialist for Hanger Prosthetics & Orthotics in New York City, where he is*

*engaged in clinical practice, research, and teaching. He is a co-inventor of the Aircast Air-limb™ IPOP. He is also a member of the American Academy of Orthotists and Prosthetists, and a professional member of the Amputee Coalition of America. John can be reached by e-mail at [jrheinstein@nyc.rr.com](mailto:jrheinstein@nyc.rr.com)*

# FACING CONGENITAL LIMB DIFFERENCES

*A Child is More Than an Arm or a Leg*

by Rick Bowers



*Katie Cofield, now 18, was born with Proximal Femoral Focal Deficiency (PFFD), a congenital condition characterized by a failure of normal development of the upper end of the thighbone and the hip joint.*

Steffini Vandever, 34, knew that something was terribly wrong shortly after the premature birth of her son, Jonah, three years ago. "The room went deadly quiet," she recalls, "as a trembling nurse brought my son for me to see. I asked the nurse if he had legs since all I could see was feet up by his face. She said, 'Yes, but they're not normal.'"

Over the next six weeks, Vandever was on an emotional roller coaster as the meaning of those words became clear. Jonah had backward knees and clubbed feet, with a missing baby toe on each foot; his hands were malformed, and he had no forehead. Tears became Vandever's constant companion.



*Jonah, 2-1/2 years old*

Other parents of newborn babies with congenital limb differences face similar emotions when they first realize that their child is different. It's normal for a parent to grieve in such a situation. And this grieving process may take a long time to work through. Parents, nevertheless, need to go through the stages of shock, denial, anger, depression, acceptance, and hope. They may even experience feelings of guilt.

Liz Uchytel (pronounced you-ka-til), 54, vividly remembers when her daughter Theresa was born without a left hand more than 20 years ago. "I was very sad. I didn't understand why it had happened. I hadn't done anything to put my child at risk for a birth abnormality; however, I



*Theresa Uchytel, age 12, with baton trophies*

blamed myself." It took Liz a year to get over her grief. Then, she says, "I decided to move on and not dwell on what she did not have, but focus on what she did have!"

Mary Williams Clark, MD, puts to rest the notion that parents are responsible for their child's congenital limb differences. "There was nothing which was under your control that you did or didn't do that caused it," she says. "There are different causes for limb deficiencies, and we don't know all of them. Some are genetic, but again, that's something that is not your fault. If you took medication or were exposed to radiation or other teratogenic substances, remember that the limbs develop in the first four to seven weeks, usually before you know you are pregnant."

## Communicating your feelings

Once a child is born with limb differences, communication is important for helping parents get through this difficult period. It may help them to discuss their feelings with loved ones, with other parents who have gone through a similar situation, or to get involved with a support group.

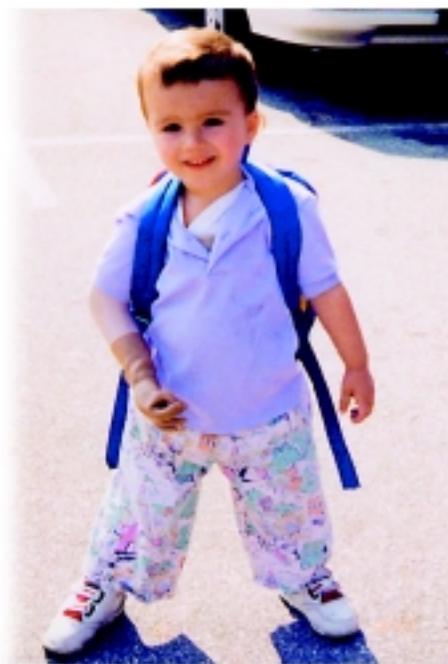
When Cheryl Leingang's 12-year-old son Kurt was born in 1988, he was missing his right forearm and hand. Leingang, 45, now realizes that she worried about "silly" things at the time. Then she and her family were invited to a meeting of a support group called *Limbs of*



*Kurt (right) and his brother, Kyle*

*Love.* “We loved being with other parents and children who understood how we felt and the challenges that we were all facing,” Leingang says. The family later helped establish a support group in Southern California called *A Touch of Love*. “We feel strongly that Kurt has benefited from knowing that he is not the only one on the planet who was born without a hand.”

Maria Foster, 41, of San Dimas, California, also considers *A Touch of Love* a blessing. After her son Zach was born without a right arm or elbow, she had a very difficult time accepting it. “I used to cry and cry,” she recalls. “Then I met Cheryl Leingang and other parents of limb-



*Zach hiking*

deficient children. I remember seeing everyone laughing and talking like nothing was wrong, and I remember being angry with them. How could they be happy when their child was handicapped? Then, somebody taught me that a baby is not an arm. Through Cheryl Leingang and the support group, I was able to see that everything would be all right and that I wasn't alone, and neither was my child.”

### Providing for your child's medical and psychological needs

Children with limb differences should be taken early to a child amputee center where they can be seen by various healthcare professionals, including a doctor, a nurse, a social worker, a psychologist, a dietician, a recreational therapist, a physical and/or occupational therapist, and maybe a prosthetist.

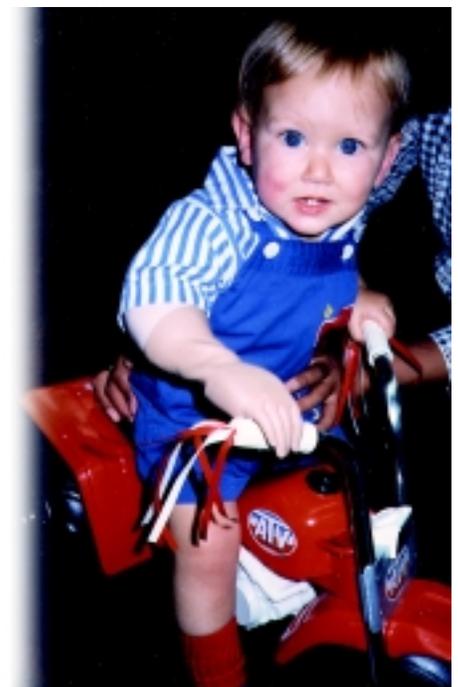
There is some debate about whether children with congenital limb differences should be fitted with prostheses early so that they can become accustomed to them and decide for themselves whether they want to continue using them or whether they should be allowed to adapt to their limb difference without prostheses. The debate seems to be more relevant for those with upper-limb differences. Lower-limb prostheses are often considered more necessary because of mobility issues.

Children with upper-limb differences can often learn to function quite well with their partial limbs, their feet, their toes, or their other arm. They can learn to hold objects under their chin, between their residual limb and chest or under their partial arms. Children are very good at adapting to their situation and often do not really need a prosthesis. In these cases, the prosthesis might really be more of an unnecessary cosmetic device than a functional one, especially since their residual limb can experience true sensations while a prosthesis cannot – a definite disadvantage. Conversely, having a cosmetic prosthesis might do wonders for the child's emotional acceptance of his or her limb difference.

Sometimes, parents opt for prostheses for their children at an early age merely because they feel pressured to do so and think it is necessary. Later, they may find out that the prostheses were unnecessary and that their children perform better without them.

Since there is no right or wrong answer to the question of whether or not to use prostheses, parents and children with limb differences will have to determine what is best for their unique situation. It is important, however, that they realize that there are alternatives and that they not be pressured into doing anything that they might later regret.

Cheryl Leingang and her husband, Alan, opted to use a prosthesis for their son. They fitted him with a passive prosthesis when he was 9 months old and a myoelectric prosthesis when he was 13 months old. “We wanted to make sure Kurt received every opportunity that was available to him,” she says. “He took to the artificial limb well and still uses a prosthesis today. We knew that if he got used to wearing the prosthesis at a young age he would have a better chance to take advantage of the modern technology that we prayed would exist in his future.”



*Kurt's first attempt to ride a bike, 1989*

### Knowledge is your best friend

Knowing what options are available is very important so that parents can make informed decisions.

Maria Foster considers the lack of information available to her when her son, Zach, was born 12 years ago as the most difficult aspect of her experience. “I had no options,” she says. “Somebody wanted to put a hook on him. I

wasn't told about reading materials; I wasn't referred to counseling; I wasn't referred to support groups, and I wasn't given information about my insurance and the coverage. I wasn't told that my marriage could be saved if we knew what was happening to us. Nothing."

Her advice to parents: "Get as much information as you can get. Get on the telephone and call prosthetists. Not doctors. They don't know everything. Get on the Internet. Talk to every social agency you can. Get counseling. Get into a support group. And most importantly, meet limb-deficient children."

Parents should look into any new treatments that might be available to help their child, but should not let themselves be rushed into anything they might later regret – especially if it is something irreversible.

## Sometimes you might have to step on a few toes

Making the right decisions for one's child might require insisting on something that traditional knowledge disagrees with.

Steffini Vandever was frightened because she had so little information about her son's problems and because no one was able to give her satisfactory answers to her questions.

At five months, doctors constructed a forehead for the child and regularly put his legs in braces to try to straighten them; however, there was little improvement, and it looked as if Jonah would never walk.

The young mother decided to stop passively accepting other people's opinions, including the

doctors', and began to educate herself. After consulting 43 doctors from around the country, Vandever made perhaps the most difficult decision of her life – the decision to ask the doctors to amputate her son's legs.

At 18 months and at Steffini's request, doctors amputated both of Jonah's legs through the knees. Soon after, he was fitted with prostheses and quickly began to walk independently.

"Get educated on what your child has," Vandever encourages parents. "The more you know, the better you will be equipped to make the right decisions. The doctors won't like it, but who cares? It's your child, not theirs."

Parents might also feel that "experts" are judging their actions too harshly, making them do things that they don't want to do, or intruding too much on their family's privacy. They may have to say when they would prefer to talk to professionals and what parts of their lives are off limits. Even well meaning people can sometimes overstep their bounds.

## Recognize your limitations, but be willing to make sacrifices

It is important for parents to realize that they cannot do everything for their child. Parents may have jobs, other children, and other things that require their time.

Parents must be aware of the potential for children to become jealous of their siblings with limb differences because they might be getting extra attention or better treatment. It is important that parents let the other children know that they are loved as well. Children with limb differences, like other children, will have days when they misbehave, and they should be disciplined just as the other children are. Parents should not be afraid to say "no" to their child just because he or she has a limb difference.

Parents should also realize that they are not just an extension of the medical team responsible for their child's care. They are also parents and sometimes need to forget the medical aspects of their child's life and just have fun with their child. Sometimes, they just need time alone or time to rest, Vandever says.

At other times, extreme sacrifices may be required to make the family function smoothly. Vandever, a single mother of three children, runs a children's day-care business from her home so

that she can spend more time with her own children. Before Jonah's birth, Vandever was pursuing a law degree in criminal justice and was about to go into the police academy. "But when my son was born with his defects," she says, "I knew the best job to have was to stay at home and be his mommy." Each parent will face different obstacles and will have to make different kinds of sacrifices, according to the needs of his or her child.

Parents should know about the numerous government agencies, disability organizations, religious organizations, Shriners hospitals, and other organizations that are available to help them with any difficulties they might face.

## As the child grows up

Parents of children born with limb differences are often surprised at how much their children can do.

Success stories usually start with the words, "We treated him just like anyone else." Children seem to do better when parents only give assistance when it is necessary and when parents don't put limitations on them.

"As Theresa grew," says Liz Uchtyil, "she was always doing things for herself. I worried that she would not be able to crawl because you need two hands and I was sure she was going to fall on her face. But, she taught herself how to crawl. Then, I worried that she wouldn't be able to walk because you need two hands for balance, but she began walking earlier than her two older sisters." Theresa also surprised her mother when she became a baton twirler at age 6, and when she later learned how to type with speed and accuracy.

Leingang advises parents of children with limb differences to watch for "extraordinary abilities that God has blessed their children with." She has found many in her son, Kurt. "He plays soccer and baseball really well," she says. "When he was 9, he became a member of the prestigious All American Boys Choir. He currently plays the cornet in his junior high concert band and jazz band. I remember a year ago when we took the instrument that my husband had used as a child to a local music shop. We asked them to 'spiff' it up. The owner of the shop said he was surprised Kurt had chosen to play the cornet because he had never



*Jonah before his legs were amputated*

heard of a left-handed trumpet player.' Kurt didn't even blink. He just looked up at the man and said, 'Well, now you have!'"

### Difficult situations for your child

Two problems those with limb differences sometimes experience are staring and teasing. Parents should, thus, prepare themselves and their children for such situations.

Maria Foster describes her experiences. "When Zach was a baby, people (children and adults) would reach up and pull up his shirt to see his arm. Children in the park would chase him to grab his arm. I'd be screaming at people in supermarkets and parks to protect him."

Cheryl Leingang's son Kurt had an older brother and sister, Kyle and Kendra, to help him. "They often answered questions for him from inquisitive children when we would go to the park," Leingang recalls. "He learned from them how to quickly dismiss it and just play along like everyone else."

Terry Haffner, a well-known public speaker and artist, was born without arms and with only partial legs. Sometimes when he was not able to wear his prosthetic arms, some of the neighborhood boys would tease him, saying, "Show us your muscle." Having a few best friends who accepted him fully made a world of difference to



*Today, Terry Haffner teaches painting at local schools.*

him, he recalls.

Parents can help prevent or dilute these problems by letting their child meet other children with limb differences, by explaining to their child that most children get teased about something, or by telling their child about their own experiences of being teased.

### Dating and romance

Dating and romance also bring up numerous issues for children with limb differences.

Jan Garrett, JD, a successful disability rights attorney, was born with no arms and only partial thighs. She chose early in life not to wear prostheses — a decision that was respected by her parents.

"I wondered if I would ever find romantic love," Garrett recalls. "In high school, I never dated. It was not until I completed college that I had my first long-term romantic relationship. My first two serious romantic relationships demonstrated how immature and inexperienced I was in selecting an appropriate partner. But even though those relationships ended badly, they demonstrated that men could be attracted to me, something that was a new concept altogether."

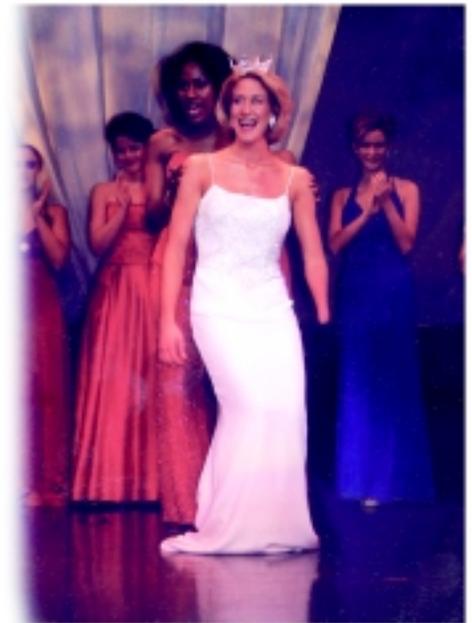
Garrett ultimately met Dan Garrett, the man who would become her husband. "The relationship Dan and I share is solidly based on true love," she says. "But it is also based on mutual physical attraction. I know Dan loves me with my disability, not in spite of it."



*Jan Garrett as a young girl (top) and on her wedding day with husband, Dan*

### Love and encouragement

It's clear that many children born with limb differences go on to live happy, fulfilling lives, and most parents realize that their children's limb differences do not have to hold them back. Terry Haffner, Jan Garrett and Theresa Uchytel — who ultimately grew up to become Miss Iowa in the 2000 Miss America Pageant, a world champion baton twirler and a program manager at Gateway Computers — are wonderful examples of how far those with limb differences can go.



*Theresa Uchytel, Miss Iowa 2000*

Mary Williams Clark, MD, sums it up quite well. "Let the children know you love them just the way they are," she says. "The most important factor influencing the eventual outcome for your child as she or he grows up is not the kind of prosthesis, not the kind of surgery, if any, not even how early he or she was seen by an experienced team, or even the extent of your child's physical differences - it's your attitude toward the situation. If you can see all your child's abilities, see her as capable, emphasize all the things he can do - if you can look at them with or without a prosthesis, in or out of the bathtub - if you can consider them normal children who happen to have their differences, that is the picture of themselves they will grow up with. Love them, challenge them, applaud them and they will develop the self-esteem and self-confidence they need."

# EARLY FITTING IS KEY TO SUCCESS

by Diane Atkins, OTR/L, FISPO

The ideal time to fit a prosthesis for a child with congenital limb deficiency is at the age of 6 to 7 months or whenever the infant is able to sit independently. Before that, however, it is necessary to orient the mother and father to the importance of prostheses and the various types and components available. Parents often have many questions and should be given adequate information early.

As an occupational therapist, I firmly believe that every child should have the opportunity to wear a prosthesis, especially early in life when, developmentally, it will be of the most benefit. If the parents wait until the child is perhaps 5 years old, the odds that the prosthesis will be sufficiently used are diminished significantly. Early fitting is clearly the most vital factor in achieving a successful outcome.

It is also essential that the person introducing prostheses to the parents be completely impartial in explaining the pros and cons of the different types. He or she should simply present all of the facts so that parents have comprehensive information upon which to base an informed decision for the child.

I have seen children do extremely well with both body-powered and myoelectric prostheses. The type of prosthesis prescribed for a child often depends on the opinions of the parents in conjunction with other members of the rehabilitation team. Each situation is highly individual.

I am personally seeing a definite trend to fit children with myoelectrics versus body-powered prostheses. Parents want “only the best” for the child and may feel that myoelectrics are the only acceptable option.

If finances are available through insurance or personal funds, I see no objection to prescribing myoelectrics.

A possible contraindication is if the deficient limb is particularly long – for example, one that includes bones of the wrist and/or hand, as in a partial hand amputation. These cases are extremely difficult to fit because of the space needed for the motor and battery of a myoelectric prosthesis. Without sufficient room, the

prosthesis could be longer than the sound side, and that would be a problem.

I recall one incident in which a little girl was limb-deficient as well as severely retarded. In this situation, a myoelectric prosthesis was inappropriate because it requires sufficient cognitive skills to learn to use this type of prosthesis. Another reason not to use a myoelectric prosthesis might be inadequate family support. Substantial one-on-one attention is needed to help a child acquire myoelectric proficiency.

Generally, pediatric myoelectrics are simple and durable enough as long as the prosthetist and therapists have oriented the parents and



Photo courtesy of Liberating Technologies, Inc.

child in the use and care of the prosthesis. Naturally, little children must avoid activities involving dirt, sand, and water when wearing a myoelectric arm; however, these factors should not deter prescribing this device.

## Fitting both types

If enough money is available, the best option is to fit the child with both a myoelectric and a body-powered limb; however, because of restrictions imposed by managed care organizations (MCOs), usually only one is permitted. Sometimes, it is difficult to get approval from an MCO for a myoelectric prosthesis. And some MCOs will only reimburse for one prosthesis in a lifetime, although that is more likely in adult cases.

MCOs are gradually recognizing that prostheses do wear out and are outgrown and that the one-per-lifetime limit is unreasonable.



Sometimes, it just requires a strongly worded letter of medical necessity from the physician to get approval for a myoelectric device. At other times, it may be hard to justify a myoelectric over a body-powered prosthesis.

The first prosthesis prescribed for infants is usually a passive hand. Then, at approximately 9 months, the child may get a single control "cookie crusher." Not until perhaps 18 months would the child receive a more complicated two-stage device. The average life span of a child's prosthesis is 1-1/2 to 2 years, depending on the child's growth rate.

One economical way to replace prostheses is a limb bank – a collection of outgrown prosthetic parts. Several chapters of the Variety Club, an organization founded in 1928 by entertainers to serve children in need, maintain such resources throughout the country. Even with this recycling of components, however, the prosthetist still must recondition them and make a new socket so the price is not greatly discounted.

A child's new below-elbow prosthesis costs approximately \$12,000-\$15,000. The price of an

above-elbow prosthesis that incorporates an electric elbow is often twice as much or more. A new myoelectric prosthesis can only be adjusted for growth up to a certain point and then it's outgrown. So, yes, the cost of pediatric myoelectric prostheses is surely a consideration.

### Looks make a difference

Why do parents insist on myoelectric prostheses? Because of the way they look. They look far more like a real hand and arm. As far as the child is concerned, it doesn't really matter – it makes a difference to the parents.

In terms of prosthetic use and proficiency, it's fine to start a child on a body-powered prosthesis and then switch to myoelectric when the youngster becomes more aware of appearances and could be self-conscious about a limb deficiency.

Most parents, however, now start children with a myoelectric prosthesis and stay with it. Unfortunately, there have been few retrospective studies done to see if the young child continues wearing the myoelectric through adulthood.

Most of our information on prosthetic use is merely anecdotal.

What we do know, however, is that early fitting is crucial. Waiting until a child is school age is not likely to be as successful. If a child is not fitted within the first two to three years after birth, the odds of successfully using a prosthesis decrease with each subsequent year.

### About the Author:



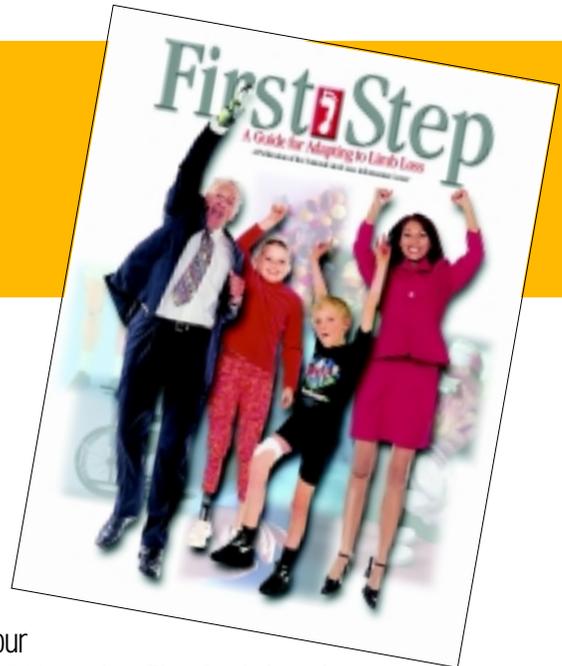
*Diane Atkins, OTR/L, FISPO, is a clinical assistant professor, Department of Physical Medicine and Rehabilitation, Baylor College of Medicine. She lives*

*in The Woodlands, Texas, and is in private practice. She may be reached via e-mail at [djatkind@yahoo.com](mailto:djatkind@yahoo.com)*

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# ASSISTIVE DEVICES GIVE UPPER-EXTREMITY AMPUTEES A HELPING HAND

*Simple, complex products make life easier for prosthetic and nonprosthetic users*

by Rick Bowers

Though upper-extremity amputees, especially those with congenital limb differences, are remarkably adaptable in most situations, they, like all human beings, sometimes need a “helping hand.” Some prefer to rely on their residual limb, their other hand, their feet, and the assistance of simple devices; others prefer to take advantage of more complex items like actual artificial hands, or prostheses. Whatever the individual amputee chooses, the necessity for assistance often leads to interesting adaptations of existing products or, in some cases, inventions.

## Simple devices to help the nonprosthetic user

Performing tasks doesn't always require complex devices. Amputees who do not want to use prostheses can often take advantage of much simpler items like shoes with Velcro laces that can be closed with one hand, double-sided tape, shirts with snaps, neck slings to help hold tools, and clip-on ties to make their lives easier. A simple cutting board with stainless-steel nails driven through it and protruding through can be used by one-armed nonprosthetic users to hold items like fruit and vegetables for cutting or peeling. Sammons Preston offers a simple device called a Pant Clip, which can help unilateral upper-extremity amputees pull up and button their own pants.

Maddak Inc., offers a one-hand cutlery set that allows one-arm amputees to use a single device to cut and eat their food and dental floss holders that make flossing possible. One of the company's more interesting devices is The

Eatery - a relatively simple device that helps bilateral upper-extremity amputees eat independently without prostheses.

Both Sammons Preston and Maddak Inc., offer elastic shoelaces that make it possible to slip in and out of shoes without tying or untying laces. Other devices from the two companies include: button loops that help upper-extremity



*Dressing Stick (Photo courtesy of Maddak Inc.)*

amputees guide buttons through buttonholes; a dressing stick that makes dressing easier, writing instruments that can be held by a toe, and adjustable head pointers or mouth sticks that can hold a pen or be used to turn pages.

For bilateral upper-extremity amputees, toileting is one of the most difficult activities. An easily installed bidet for the commode in the home can be very useful. With certain models, the control handle, which controls the water stream and the air for drying, can be manipulated using a mouth stick with a long metal hook.

On the more-complex end of the spectrum are devices like self-propelled lawn mowers, which can be purchased from numerous companies, and the Winsford Feeder, an automatic setup that helps people with no arms eat independently. A switch can be activated by a head or chin motion, which causes a spoon to go to the food and bring it back to the mouth of the user. The Winsford Feeder is available from Sammons Preston.



*The Eatery (Photo courtesy of Maddak Inc.)*



*The Winsford Feeder*  
(Photo courtesy of Sammons Preston)

## Taking advantage of computer technology

Computers are everywhere today and the ability to use them can open up the world for upper-extremity amputees, giving them access to information, a social life, and even employment. For people with no hands or only one hand, however, using a computer that requires typing on a keyboard and moving a mouse may seem almost impossible. Although some amputees type with a one-handed keyboard or with a pen or pencil held between their teeth, the need or desire for something more efficient has again led to invention. Many products exist now that allow computers to be set up to operate totally hands-free - no prosthesis required!

Words+ and Origin Instruments Corporation offer the wireless HeadMouse, which can, as the name implies, be operated by movements of the user's head. A sip/puff switch or software can be used to perform the clicking function. The HeadMouse can also be used with an on-screen keyboard, which helps the user write letters and use the Internet. Madentec Limited, Advanced Peripheral Technologies, and numerous other companies have similar devices available.

The Propagated Development Group and



*Head Mouse* (Photo courtesy of Origin Instruments Corporation)

Hunter Digital offer a foot-controlled mouse, and The Propagated Development Group offers TouchKeys, a product that allows users to type with a mouse.

An Infrared/Sound/Touch (IST) Switch, available from Words+, and the Eyegaze System, distributed by LC Technologies, Inc., make it possible for computer users to operate numerous devices and software with the blink of an eye or almost any type of body movement. Some might also want to consider speech-recognition or voice-activated software, which is offered by several companies. Some programs even allow users to do computer programming.



*N-Abler II* (Photo courtesy of Texas Assistive Devices)

## Those who prefer prostheses

Some amputees prefer to use prosthetic devices, like artificial hands, hooks, prehensors, or other terminal devices.

For example, amputee Edward Niziol's favorite meal was a good steak dinner; however, it was difficult for him to manipulate the steak knife with his prosthetic hand. So he invented and patented a prosthetic knife to insert in his prosthetic arm to give himself and other amputees better control when cutting their food. When not eating, the amputee can simply push a lever on the prosthesis, and the knife moves out of sight.

Amputee Ron Farquharson, co-owner of Texas Assistive Devices, LLC, also wanted a product that could help him cut things, but, ultimately, he invented a product that could do much more. In 1991, Farquharson (pronounced far-kwer-sun) co-invented the N-Abler - a terminal device for the end of an arm prosthesis that is a stable holder for a variety of interchangeable tools. Over 100 tools, such as specially modified wrenches, pliers, hammers, knives, forks, spoons, fishing rods, and garden-

ing tools, are now available for the device.

While the prosthetic knife and the N-Abler allow single-function tools to be used on the end of a prosthesis, hooks and prehensors like the GRIP and the Electric Greifer (Gripper) are functional terminal devices that perform many tasks.

Hosmer Dorrance Corporation and United States Manufacturing Company (USMC) both offer hooks, which are typically body-powered, but sometimes electric.

David W. Dorrance, the original designer of the "Split Hook," patented the device in 1912. Dorrance, who had lost his hand in 1909 in a sawmill accident, was unhappy with the immovable single hooks of the time that were similar to the well-known "pirate's hook," so he went to work to produce something better. The split hook design he developed offered much more functionality in that it allowed the hook to be used for more than merely hooking onto things; the split hook allowed items to be squeezed and held between the hooks. Today, the company offers a wide variety of split hook designs.

Though many people prefer artificial hands for cosmetic purposes and, in the case of electric arms, for greater grip, the split hook also has many advantages. Using a hook, amputees can better see what they are trying to hold, while the size and thickness of artificial hands sometimes block their view. Because artificial hooks and hands can't feel, being able to see what one is doing is important. This also makes hooks generally better for picking up smaller objects. Also because hooks are usually made of metal, amputees don't have to be as careful around heat, which can melt artificial hands.

Among Hosmer Dorrance's most popular hooks is the No. 7. "I call the No. 7 hook the Swiss Army Knife of prosthetic hooks," says John Michael, CPO and president of CPO Services Inc., an independent consulting firm. The No. 7 hook includes a pail hook, a nail and chisel holder, and a knife grip as part of the hook and has a wider opening to allow for holding things like shovels and broom handles. A quick-disconnect wrist offered by the company allows users to switch from a hook to a regular hand with the push of a button.

USMC also offers a body-powered split hook

and quick-disconnect wrist, as well as an easy-flex wrist that allows amputees to flex and lock their wrist at 45- and 65-degree angles so that they can better reach the midline of their body with their hook.

Somewhere between a hook and a hand are



*A prosthetic hand, a standard hook and a quick-disconnect wrist from USMC (Photo courtesy of USMC)*

devices called prehensors, like the GRIP, which is produced by TRS Inc., and the Electric Greifer, which is produced by Otto Bock. These devices consist of a thumb-like component and a finger component and resemble lobster claws or pliers.

These devices are not as cosmetically pleasing as artificial hands, but like hooks, they are better able to offer visual feedback to the amputee.

While most hooks are voluntary-opening, which means that the user must apply force to open the hook which then closes on its own with the aid of rubber bands, the GRIP is a voluntary-closing device, meaning that force must be applied to close it instead of to open it. Voluntary-opening devices are limited in their closing strength by the strength of the bands. Voluntary-closing devices, on the other hand, are only limited by the user's strength and can be controlled



*The Grip 3 (left) and the Grip 2S from TRS, Inc. (Photo courtesy of TRS)*

incrementally. In addition to visual feedback, voluntary-closing devices provide a tension feedback similar to the "feeling" experienced when using bicycle handbrakes.

The Electric Greifer has a number of additional advantages: It is voluntary-opening and voluntary-closing, it allows very wide opening, it includes built-in wrist flexion, it is battery-powered, and it is myoelectric, which allows it to take advantage of the body's own muscles for control. Its disadvantages are its heavy weight and its inability to be immersed in water.

Some amputees choose to use hooks or



*The Electric Greifer (Photo courtesy of Otto Bock)*

prehensors like the GRIP or Greifer, while others choose to use artificial hands. It is a matter of choice and depends a lot on what the amputee needs. In some cases, amputees choose to use different devices for different purposes.

By taking advantage of the myriad devices available to help them, upper-extremity amputees - whether they wish to use prostheses or not - should be able to accomplish almost any task. Sometimes, though, when no satisfactory product exists, amputees might have to do what Edward Nizio, Ron Farquharson, David W. Dorrance, and Bob Radocy (the inventor of the GRIP) did - they might just have to invent their own.

## Manufacturers and Distributors of Assistive Devices for U/E Amputees

### Advanced Peripheral Technologies

708/301-4508  
www.advancedperipheral.com/gyro.htm

### Edward Nizio

716/745-1497  
E-mail: NizioLynch@aol.com

### Hosmer Dorrance Corporation

1-800/827-0070  
www.hosmer.com

### Hunter Digital

310/476-1874  
www.nohandsmouse.com

### LC Technologies, Inc.

703/385-7133  
E-mail: requests@eyegaze.com

### Maddak Inc.

973/628-7600  
www.maddak.com

### Madentec Limited

780/450-8926  
www.madentec.com

### Origin Instruments Corporation

972/606-8740  
www.orin.com

### Otto Bock

1-800/328-4058  
www.ottobockus.com

### The Propagated Development Group

636/271-9760  
www.touchtime.com

### Sammons Preston

1-800/323-5547  
www.sammonspreston.com

### Texas Assistive Devices, LLC

979/798-8809  
www.tgn.net/~pbetts/

### TRS Inc.

1-800/279-1865  
www.oandp.com/trs

### United States Manufacturing Company (USMC)

626/796-0477  
www.usmc.com

### Words +

1-800/869-8521  
www.words-plus.com